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**End of Life Care**

When a loved one is dying, conversations about the end of life can be difficult and uncomfortable. Still, discussing the end-of-life care is important. You may be able to help your loved one make important end-of-life decisions….such as whether to remain in the home, or move to a nursing/other facility or seek hospice care. Work with your loved one’s health care team to ensure comfort at the end of life. We need to still support and nurture our loved ones, simply being there can be an important source of comfort for everyone.



**What is end-of-life care? What are advance directives?**

End-of-life care is a general term that refers to the medical and psychosocial care given in the advanced or terminal [stages](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?term=stage&version=Patient&language=English) of illness. Advance directives are the legal documents, such as the living will, durable power of attorney and health care proxy, which allow people to convey their decisions about end-of-life care ahead of time. Advance directives provide a way for patients to communicate their wishes to family, friends, and health care professionals and to avoid confusion later on, should they become unable to do so. Ideally, the process of discussing and writing advance directives should be ongoing, rather than a single event. Advance directives can be modified as a patient's situation changes. Even after advance directives have been signed, patients can change their minds at any time.

**What is a living will?**

A living will is a set of instructions documenting a person's wishes about medical care intended to sustain life. It is used if a patient becomes terminally ill, incapacitated, or unable to communicate or make decisions. Everyone has the right to accept or refuse medical care. A living will protects the patient's rights and removes the burden for making decisions from family, friends, and physicians.

There are many types of life-sustaining care that should be taken into consideration when drafting a living will. These include:

* the use of life-sustaining equipment ([dialysis](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?term=dialysis&version=Patient&language=English) machines, ventilators, and respirators);
* "do not resuscitate" orders; that is, instructions not to use CPR if breathing or heartbeat stops;
* artificial [hydration](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?term=hydration&version=Patient&language=English) and [nutrition](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?term=nutrition&version=Patient&language=English) (tube feeding);
* withholding of food and [fluids](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?term=fluids&version=Patient&language=English);
* palliative/[comfort care](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?term=comfort%20care&version=Patient&language=English); and
* [organ](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?term=organ&version=Patient&language=English) and [tissue](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?term=tissue&version=Patient&language=English) donation.

It is also important to understand that a decision not to receive "aggressive medical treatment" is not the same as withholding all medical care. A patient can still receive [antibiotics](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?term=antibiotic&version=Patient&language=English), nutrition, pain medication, [radiation therapy](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?term=radiation%20therapy&version=Patient&language=English), and other interventions when the goal of treatment becomes comfort rather than cure. This is called [palliative care](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?term=palliative%20care&version=Patient&language=English), and its primary focus is helping the patient remain as comfortable as possible. Patients can change their minds and ask to resume more aggressive treatment. If the type of treatment a patient would like to receive changes, however, it is important to be aware that such a decision may raise insurance issues that will need to be explored with the patient's health care plan. Any changes in the type of treatment a patient wants to receive should be reflected in the patient's living will.

Once a living will has been drawn up, patients may want to talk about their decisions with the people who matter most to them, explaining the values underlying their decisions. Most states require that the document be witnessed. Then it is advisable to make copies of the document, place the original in a safe, accessible place, and give copies to the patient's doctor, hospital, and next of kin. Patients may also want to consider keeping a card in their wallet declaring that they have a living will and where it can be found.

**Chicago End of Life Coalition – Local Resource**

Chicago End-of-Life Care Coalition organized in January 2000 in response to a national call for local community education efforts to improve care for the dying.

Answering the call associated with the PBS television documentary series *On Our Own Terms: Moyers on Dying in America,* CECC began as a grassroots effort that was the first step toward establishing an ongoing coalition of like-minded organizations and facilities.

Today CECC is an all-volunteer not-for-profit corporation, governed by a board of directors that includes some of Chicago’s most dedicated and talented healthcare representatives and a membership that encompasses people and providers from every walk of life.

Many of our members work with dying patients, their families and spiritual counselors who face the difficult task of making appropriate decisions and provide guidance, direction or support

**Where to Start**  
*(by Dale. G. Larson, Ph.D. Reprinted with permission from the Partnership for Caring, Inc.)*  
Here are tips to help you talk to doctors, loved ones – and yourself:

* **Know your stuff:** Research your disease and take a detailed list of questions to your doctor. If you need support, take along a friend or family member. Ask to tape record the medical interview so you can remember all the details of the conversation. Understanding what to expect and what you can do to increase your loved one’s comfort can help.
* **Build teams:** When you talk to your doctor, nurses, social workers, clergy and other caregivers, think of them as colleagues, all interested in the same thing – helping you live your life to the fullest in the time you have left.
* **Learn from others:** Call a local hospice or hospital to find support groups or education programs for people facing the same medical or caregiving challenges you are.
* **Share experiences:** Get your group – say, church or senior center – to discuss the experiences (good and bad) that members have had with friends and family who have died recently.
* **Plan proactively:** Discuss a treatment plan for your remaining time with your loved ones. Discuss your medical options (living will and healthcare proxy) and desired funeral arrangements. Give your doctor a copy of your completed directives.
* **Don’t waste time:** Share with your loved ones what you’d like to do with the remaining time in your life – travel or getting together with old friends, for example. Be realistic, but set down your plans in detail and take action.
* **Tie up loose ends:** Think about what the unresolved issues are for you and your family, and what you can do to achieve some closure. Discus important life events or unsaid thoughts to help provide closure for everyone. For example, tell someone you forgive him or her for a past conflict. Get closure for the unfinished parts of your life.
* **Tell your story:** Make a video or audiotape for your children or grandchildren, telling them stories of your life and candidly sharing your feelings for them.
* **Write it down:** Think of writing as a conversation with yourself. Writing about your life in its final stages may not cure your illness, but finding words to describe what you’re feeling can be emotionally comforting and help you find meaning.
* **Look for the window of opportunity:** If your illness worsens and you are trying to balance life-prolonging treatments with your quality of life, it might be time for you to consider dying as the next stage of your life. The more you talk with others and prepare, the more likely you are to be able to maintain control and dignity and achieve a sense of peacefulness in the time that remains. Maintaining that control gives those nearing the end of life a sense of being comfortable with what is soon to come.

**Choosing Where to die:**

When discussing options with your loved ones, consider their preferences and well as any special physical, emotional and/or psychosocial needs. Make sure the other family members are aware of how much support/care they can provide to the client. Family may ask for a referral to palliative or hospice care specialists who may also be helpful in making these decisions.

**-Home Care**🡪 Many people choose to die at home or in a family member’s home. Family can assume the roles of care givers or hire care givers for their loved ones. Hospice care can be provided at home as well.

-**Inpatient Care🡪** Around-the clock care is an option as well; at a nursing home, hospital or dedicated inpatient hospice facility.

**Spirituality**

The topic of spirituality may come up in conversation with your loved ones. Do not force the subject, but your loved one may want to have visits by spiritual leaders when nearing the end of life. You might also ask open-ended questions about his or her beliefs, feelings, experiences or most meaningful moments.

**Saying Goodbye**

Encourage your love one to communicate his or her final wishes and share their feelings (ex. thanks/forgiveness) and give others (family and friends) a chance to say goodbye. Your loved one may want to leave some type of legacy; letters to family or a recording about his or her life, especially about any important future events that will be missed. Leaving legacy may also help the dying feel as though they will not be forgotten if they leave some type of positive reminder for their family and friends. Doing so may stimulate discussions about important events or unsaid thoughts which can be meaningful and helpful for everyone.

<http://www.cecc.info/end-of-life-care>

<http://www.cancer.gov/cancertopics/factsheet/Support/advance-directives>

<http://www.youtube.com/watch?feature=fvwp&v=Z08V0ciiZLM&NR=1>

<http://www.cecc.info/about>

<http://www.mayoclinic.com>

<http://www.nhpco.org>

<http://www.hlm.nih.gov>